

Quality of Life in Parents of Children With Autism Spectrum Disorder Compared to Parents of Children With Intellectual Disabilities

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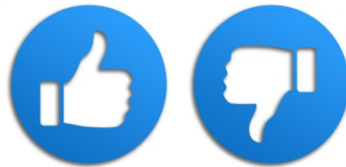
Parents of children with disabilities

- Parents of children with ASD and parents of children with intellectual disabilities go through difficult and stressful times
 - Child with ASD may have several unusual behaviors (lack of social or emotional reciprocity, agitation, difficulties related to feeding and toilet training, disturbed sleep, etc.)
 - As for the children with intellectual disabilities, they have a delay in all areas of their development, need stimulation and often have motor problems that undermine their autonomy.
 - Basic needs + special needs
 - Caring for a child with special needs demand a lot of time and energy and this could affect the quality of life of the caregiver
- Most research has focused on their coping strategies of these parents, but little research has focused on their quality of life from a multidimensional perspective



Quality of life

- The quality of life of parents of children with special needs is influenced by the characteristics of their child's disorder and the special needs of the child
- Studies support that the severity of the symptoms has a direct effect on the quality of life of the parents, mainly mothers, since they are the ones who care for the child the most



Objective

- The primary objective of this study was to compare the quality of life of parents with children with autism spectrum disorder to parents whose children have an intellectual disability



Method & Participants

- Seven Quebec mothers with a child with ASD and seven Quebec mothers with a child with intellectual disabilities aged between 4 and 21 years old
- The mothers were asked to rate their agreement for 102 situations presented regarding 10 areas of their quality of life, using a four-point Likert scale ranging from "strongly disagree" to "strongly agree"



Quality of life from a multidimensional perspective

1. Daily life activities
2. Leisure activities and relaxation
3. Job and professional relationships
4. Social activities and relationships
5. Friendly relations
6. Family activities and relationships
7. Parent-child relationships (relations with the child who has ASD or an intellectual disability)
8. Couple relations
9. Well-being
10. Self-fulfilment



Quality of life scale for parents



- Quality of life scale for parents
 1. Scale designed to assess the consequences of disability on the daily lives of parents having children with special needs such as ASD or intellectual disability
 2. The parent is asked to give their degree of agreement on for each of the 102 situations presented that reflect the 10 areas mentioned earlier
- The higher the score, the more the diagnosis of the child interferes with the daily life of the parent as a whole



Results

- Differences in average scores for each of the domains were noted between mothers who have a child with ASD and mothers whose child has a developmental disability
- Among the 10 areas of quality of life that were assessed:
 1. Mothers of children with ASD report a higher score in **8 out of 10 domains**, which means that these 8 domains are more affected in mothers who have a child with ASD than in those with a child who presents an intellectual deficiency because the behaviors or gains associated with the development of ASD are unpredictable, strengths and weaknesses, not like children with intellectual disabilities, who are late but stable, affecting more areas of quality of life

Quality of life from a multidimensional perspective

1. Daily life activities
2. **Leisure activities and relaxation**
3. **Job and professional relationships**
4. **Social activities and relationships**
5. **Friendly relations**
6. **Family activities and relationships**
7. **Parent-child relationships (relations with the child who has ASD or an intellectual disability)**
8. **Couple relations**
9. Well-being
10. **Self-fulfilment**





Results

- Differences in average scores for each of the domains were noted between mothers who have a child with ASD and mothers whose child has an intellectual disability
- Among the 10 areas of quality of life that were assessed:
 2. **Daily life** seems more affected for the mothers of a child with an intellectual disability compared to those who have a child with ASD
 3. **Well-being** is similarly affected in mothers who have a child with ASD and those with a child with a developmental disability



Results

- Difference between the 10 domains of quality of life of mothers of children with ASD and mothers of children with intellectual disabilities : **not statistically significant**
- Difference regarding the overall quality of life of mothers of children with ASD and mothers of children with intellectual disabilities : **not statistically significant**



Discussion

- Despite the fact that the diagnosis of their child is not the same, the fact that children have the same level of autonomy could underline the influence on the quality of life of the mother
- Given the very small sample that we had access to, the differences we found were not statistically significant



Conclusion

- Mothers of children with ASD report a higher score in **8 out of 10 domains**, which means that these 8 domains are more affected in mothers who have a child with ASD than in those with a child who presents an intellectual deficiency
- The parents of children with autism are often confronted to painful situations such as sleep disorders, agitation, stereotyping, self-mutilation, learning difficulties, difficulties in feeding and sphincter education, temper tantrums, lack of reciprocity and unusual behaviors. The repercussions are economic, physical, social and psychological and the family's life tends to be organized entirely around the child and his future

References

- Poirier, N., Belzil, A., & Cappe, É. (2018). Qualité de vie des mères d'enfants présentant un trouble du spectre de l'autisme (TSA) alors qu'ils fréquentent une classe spéciale de niveau primaire ou secondaire. *Journal de Thérapie Comportementale et Cognitive*, 28(3), 141-151.
- Cappe, É., Bobet, R., et Adrien, J. L. (2009). Psychiatrie sociale et problèmes d'assistance qualité de vie et processus d'adaptation des familles d'un enfant ayant un trouble autistique ou un syndrome d'asperger. *La psychiatrie de l'enfant*, 52(1), 201-246.
- Cappe, É., Wolff, M., Bobet, R. et Adrien, J-L. (2012). Étude de la qualité de vie et des processus d'ajustement des parents d'un enfant ayant un trouble autistique ou un syndrome d'Asperger : effet de plusieurs variables socio-biographiques parentales et caractéristiques liées à l'enfant. *L'Évolution Psychiatrique*, 77(2), 181-199.
- Poirier, N., et Kozminski, C. (2008). *L'autisme, un jour à la fois*. Presses de l'Université Laval.
- Poirier, N. et des Rivières-Pigeon, C. (2013). Les aspects positifs et les difficultés de la vie des parents d'enfants ayant un TSA. *Revue québécoise de psychologie*, 34(3), 1-8.
- Sénéchal, C. et des Rivières-Pigeon, C. (2009). Impact de l'autisme sur la vie des parents. *Santé mentale au Québec*, 34(1), 245-260.